

1 AMENDMENT TO HOUSE BILL 5870

2 AMENDMENT NO. _____. Amend House Bill 5870 by replacing
3 everything after the enacting clause with the following:

4 "Section 5. The Phenylketonuria Testing Act is amended
5 by adding Section 1.5 and changing Section 2 as follows:

6 (410 ILCS 240/1.5 new)

7 Sec. 1.5. Definitions. In this Act:

8 "Accredited laboratory" means any laboratory that holds a
9 valid certificate issued under the Clinical Laboratory
10 Improvement Amendments of 1988, 102 Stat. 2903, 42 U.S.C.
11 263a, as amended, and that reports its screening results by
12 using normal pediatric reference ranges.

13 "Expanded screening" means screening for genetic and
14 metabolic disorders, including but not limited to amino acid
15 disorders, organic acid disorders, fatty acid oxidation
16 disorders, and other abnormal profiles, in newborn infants
17 that can be detected through the use of a tandem mass
18 spectrometer.

19 "Tandem mass spectrometer" means an analytical instrument
20 used to detect numerous genetic and metabolic disorders at
21 one time.

1 (410 ILCS 240/2) (from Ch. 111 1/2, par. 4904)

2 Sec. 2. The Department of Public Health shall administer
3 the provisions of this Act and shall:

4 (a) Institute and carry on an intensive educational
5 program among physicians, hospitals, public health nurses and
6 the public concerning the diseases phenylketonuria,
7 hypothyroidism, galactosemia and other metabolic diseases.
8 This educational program shall include information about the
9 nature of the diseases and examinations for the detection of
10 the diseases in early infancy in order that measures may be
11 taken to prevent the mental retardation resulting from the
12 diseases.

13 (a-5) Beginning July 1, 2002, provide all newborns with
14 expanded screening tests for the presence of genetic,
15 endocrine, or other metabolic disorders, including
16 phenylketonuria, galactosemia, hypothyroidism, congenital
17 adrenal hyperplasia, biotinidase deficiency, and sickling
18 disorders, as well as other amino acid disorders, organic
19 acid disorders, fatty acid oxidation disorders, and other
20 abnormalities detectable through the use of a tandem mass
21 spectrometer. If by July 1, 2002, the Department is unable to
22 provide expanded screening using the State Laboratory, it
23 shall temporarily provide such screening through an
24 accredited laboratory selected by the Department until the
25 Department has the capacity to provide screening through the
26 State Laboratory. If expanded screening is provided on a
27 temporary basis through an accredited laboratory, the
28 Department shall substitute the fee charged by the accredited
29 laboratory, plus a 5% surcharge for documentation and
30 handling, for the fee authorized in subsection (e) of this
31 Section.

32 (b) Maintain a registry of cases including information
33 of importance for the purpose of follow-up services to
34 prevent mental retardation.

1 (c) Supply the necessary treatment product where
2 practicable for diagnosed cases for as long as medically
3 indicated, when the product is not available through other
4 State agencies.

5 (d) Arrange for or provide public health nursing,
6 nutrition and social services and clinical consultation as
7 indicated.

8 (e) Require that all specimens collected pursuant to
9 this Act or the rules and regulations promulgated hereunder
10 be submitted for testing to the nearest Department of Public
11 Health laboratory designated to perform such tests. The
12 Department may develop a reasonable fee structure and may
13 levy fees according to such structure to cover the cost of
14 providing this testing service. Fees collected from the
15 provision of this testing service shall be placed in a
16 special fund in the State Treasury, hereafter known as the
17 Metabolic Screening and Treatment Fund. Other State and
18 federal funds for expenses related to metabolic screening,
19 follow-up and treatment programs may also be placed in such
20 Fund. Moneys shall be appropriated from such Fund to the
21 Department of Public Health solely for the purposes of
22 providing metabolic screening, follow-up and treatment
23 programs. Nothing in this Act shall be construed to prohibit
24 any licensed medical facility from collecting additional
25 specimens for testing for metabolic or neonatal diseases or
26 any other diseases or conditions, as it deems fit. Any person
27 violating the provisions of this subsection (e) is guilty of
28 a petty offense.

29 (Source: P.A. 83-87.)

30 Section 99. Effective date. This Act takes effect upon
31 becoming law."